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Impact of a Community-based Breast Cancer Screening Program on Hopi Women

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Abstract

Objective—To examine changes in breast cancer knowledge, attitudes, beliefs and behaviors following implementation of a tribal run CDC Breast and Cervical Cancer Program (BCCP), we report 2006 survey results from Hopi women and contrast findings with 1993 survey data and BCCP reports.

Methods—Community meetings, focus groups, and researchers jointly developed a culturally appropriate survey instrument. Hopi women randomly selected from Tribal enrollment lists were interviewed in-person by Hopi interviewers; 250 women \geq age 18 participated (87% response) between June and December, 2006.

Results—Among women 40+, 77.5 % reported ever having had a mammogram and 68.9% reported having done so within the past two years, an increase from 45.2% and 46% self-reported in 1993. Compared to 1993, more women in 2006 (88.1% vs. 59%) believed that a mammogram can detect cancer and more than 90% now believe that early detection of cancer can save lives. Women reported a preference (60%) for receiving health care at the Hopi BCCP. Survey results were validated using programmatic data which estimated 76.6% of Hopi women had received mammography screening.

Conclusion—Implementation of a tribal run BCCP has resulted in a substantial increase in mammography screening on the Hopi reservation.

Keywords

American Indian; breast cancer; mammography; cancer screening

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Disclosure Statement:

The authors declare that there are no conflicts of interest.

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INTRODUCTION

While early detection of breast cancer by routine mammography has been shown to reduce breast cancer mortality (Nutting et al, 1994), American Indian (AI) women are less likely to be screened (Carney M, et al, 2002, Sellers T. et al, 2002). Rates in the Southwest are about 15% lower than that for non-Hispanic Whites (NHW) (Espey, D. et al, 2007). The breast cancer incidence rate is lower among AI women but AI women are diagnosed at later stages (Espey, D. et al, 2007) and begin treatment later (Wilson RT, 2007). Their five year survival rate is only 68.9% compared with 81.5 % for NHW (Clegg LX, et al, 2002). Breast cancer remains the leading cause of cancer deaths among AI women (Espey, D. et al, 2007, <http://www.azdhs.gov/plan/report/hspam/hspam06/>).

In 1996, the Hopi Tribe received funding from the Centers for Disease Control and Prevention (CDC) for a Breast and Cervical Cancer Program (BCCP) after a 1993 community survey of Hopi women reported a 50% screening rate (Guiliano A, et al, 1998). In 2003, the Hopi Women's Health Program (HWHP), requested assistance from the Native American Cancer Research Partnership (NACRP) -a National Cancer Institute funded research collaboration between the University of Arizona (UA) Arizona Cancer Center (AzCC) and Northern Arizona University (NAU) -to provide assistance in evaluating the HWHP program and to conduct a cross sectional survey to assess the program's impact on Hopi women's knowledge, attitudes, beliefs and behaviors (KABB) about breast and cervical cancer. We report these results and contrast the findings with the 1993 survey.

METHODS

The HWHP staff, NACRP faculty, and the Hopi community jointly created a culturally and temporally appropriate survey. The instrument consisted of 103 questions on demographics, screening and health status.

Participants were Hopi women, age 18+, randomly selected from Hopi tribal rolls, who were living on the Hopi reservation at the time of recruitment. The sample was proportional to the size of the on-reservation population of women 18+ enrolled in each of the eleven Hopi villages. Approximately 27% (n=107) of those randomly selected (n=394) were ineligible to participate, due, primarily, to residency off the reservation. Approximately 87% (n=250) of those eligible (n=287) participated in the study. Interviews were conducted at home, in English and/or Hopi, by Hopi women trained in the recruitment and survey process. Three attempts were made to contact potential participants. Informed consent was obtained from each participant. Interviewees received \$25 in appreciation of their participation. Responses from one participant were sparse, leaving 249 for analysis.

Approvals for this research were obtained from Hopi Tribal Council, NAU and UA Institutional Review Boards (IRB), and the Phoenix Indian Health Service. Access to all forms and listings was limited to the HWHP staff.

Data were analyzed using Stata 8.2 and SAS 9.1. Counts and frequencies were analyzed by group: total, women ages 40+, and users of HWHP services. Differences in proportions were assessed using Chi Square. Age adjusted odds ratios (OR) and 95% confidence intervals (CI) were calculated for mammogram screening (ever/never and within past two year) using unconditional multiple logistic regression, with age entered as a continuous variable.

Findings were contrasted with published results from the 1993 survey (Guiliano A et al, 1998) and compared to screening performance data submitted by the HWHP to the CDC and analyzed by this research team (Brown S et al 2007).

RESULTS

Survey participants (Table 1) were primarily high school graduates aged 40+ (61%). Many (15%) spoke English and Hopi at home and reported using the services of a traditional healer (33%). More than 20% lived greater than 20 miles from the nearest medical facility, 33% did not own a reliable vehicle, and 15% indicated problems with transportation to health care facilities.

Table 1 also shows that among women 40+, 78.0% reported mammogram screenings and 70% reported a mammogram within the past two years. This rate was 12% higher among those who utilized the HWHP. The 23 women age 40+ who never had a mammogram failed to do so because they were never told to do so (21%), they were too scared (12%) and thought they were too young (12%).

A high percentage (97%) of Hopi women knew that clinical breast exams (CBE) and mammograms are early detection methods for breast cancer and more than 50% thought CBEs should occur yearly. Approximately 80% of all women believed that they could act to reduce their own risk of cancer. Almost 97% believed that early detection of cancer can save lives and 87% believed that a mammogram can detect cancer. Barriers to screening were embarrassment (11%) and fear (15%).

Among women age 40+, the availability of reliable transportation, using a traditional healer, breast cancer knowledge, a history of cervical and clinical breast cancer screening, and belief that a mammogram can detect cancer, were positively associated with mammogram screening within the past two years (Table 2). Embarrassment and fear were negatively associated with screening among women 40+. Women who reported ever having used the services of the HWHP were over 12 times more likely to report a mammogram within the past two years.

Compared to the 1993 survey (Guiliano A, et al, 1998), this survey found a 40% increase in women 40+ screened by mammography within the past two years (from 26% to 69%) with increases observed across all age groups. Almost 30% more women believed that a mammogram can detect cancer (1993: 59% vs. 2006: 88%). Large increases in knowledge about the mammogram procedure (1993: 56% vs. 2006:82%) and the recommended frequency of mammograms (1993: 46% vs. 2006: 66%) were also observed. No changes were observed in the percentage of women who would refuse a breast exam performed by a male (1993: 32% vs. 2006:35%)

DISCUSSION

Our survey was designed to examine changes in breast cancer knowledge, attitudes, beliefs and behaviors after the 1996 implementation of a BCCP Program by the Hopi tribe. Among women age 40+, there was a 20% increase in the percent reporting mammograms, and similar increases in the percent of women who believe that a mammogram can detect cancer and that early detection of cancer can save lives compared to 1993 survey results. Fear and embarrassment, plus transportation availability remain barriers to screening.

We validated survey results against programmatic data submitted by HWHP to the CDC. For example, from 1997–2005, 1,038 Hopi women had mammograms through the HWHP (Brown S, et al 2006), representing approximately 77% of Hopi women, the same percentage found in the survey. Program data indicated that 59% of mammograms were performed at the HWHP; 58% of survey participants identified HWHP as the site of their last mammogram..

This study had an outstanding response rate (87%) and reflects the implementation of a scientifically rigorous study which remained respectful of tribal sovereignty and included extensive community collaboration. Limitations include wide confidence intervals for comparisons with women age 40+ (n=151) and inability to assess temporal relationships between screening behavior and knowledge.

CONCLUSION

Implementation of the Hopi breast cancer screening program was associated with substantial increases in mammography screening and with increases in breast cancer knowledge and a positive change in beliefs. The success of the HWHP is evidence of the impact a tribally run program can have on cancer screening among Native Americans.

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Universe: Total population, Data Set: Census 2000 American Indian and Alaska Native Summary
File (AIANSF) - Sample Data

Table 1

Hopi Women's Survey 2006: Descriptive Results (Hopi Tribe, USA)

	All Women (n=249) %	All Women Age 40+ (n=151) %	Attendees of Healthy Hopi Women Program Users 40+ (n=85) %
RESPONDENT CHARACTERISTICS			
AGE, years			
<30	18.6	-	-
30-39	20.6	-	-
40-49	22.6	37.1	32.9
50-59	14.1	23.2	28.2
60-69	10.5	17.2	18.8
70 +	13.7	22.5	20.0
EDUCATION			
< High school	22.1	24.5	20.0
High school graduate	26.1	23.2	21.2
> High school	39.0	35.8	42.4
4 year college graduate or more	12.9	16.6	16.8
MARITAL STATUS			
Single	41.0	29.1	29.4
Married ^a	39.0	43.1	43.5
Widowed	10.0	15.9	12.9
Divorced/Separated	10.0	11.9	14.1
EMPLOYMENT STATUS			
Full-time	43.2	40.1	42.2
Part-time	10.8	11.6	13.3
Disabled/Retired/Not Working	44.8	48.3	44.6
Student	1.2	-	-
INCOME			
< \$25,000	71.4	70.7	68.2
\$25,000-\$49,999	21.4	23.2	25.9
\$50,000 or more	3.6	4.0	3.5
Don't know/Refused	3.6	2.0	2.4
PRIMARY LANGUAGE SPOKEN AT HOME			
English	47.0	32.45	36.5
Hopi	16.9	24.5	28.2
Tewa	0.8	1.3	1.2
Hopi/English	32.1	38.4	32.9
Tewa/English	1.6	1.99	-

	All Women (n=249) %	All Women Age 40+ (n=151) %	Attendees of Healthy Hopi Women Program Users 40+ (n=85) %
Other	1.6	1.3	1.18
DISTANCE TO CLOSEST MEDICAL FACILITY			
0–10 miles	55.7	58.0	56.5
11–20 miles	19.4	17.3	20.0
21–30 miles	4.8	4.0	5.9
41–50 miles	5.7	7.3	5.9
> 50 miles	12.1	11.3	8.2
Don't know	2.4	2.0	3.5
TRANSPORTATION			
Owens a reliable vehicle	61.0	67.6	74.1
Trouble getting ride to healthcare clinic	15.7	15.2	16.5
INSURANCE ^b			
Arizona Medicaid (AHCCCS)	38.6	29.8	25.9
Medicare	11.7	19.2	16.5
Private	23.7	29.1	30.6
Other	6.8	6.6	5.9
USES SERVICES OF A TRADITIONAL HEALER OR MEDICINE PERSON			
Never	26.1	30.5	25.9
Rarely	34.9	34.4	32.9
Sometimes	27.3	25.8	27.1
Often	8.8	5.3	9.4
Always	2.4	3.3	3.5
Don't Know	0.4	0.7	1.2
SCREENING HISTORY			
Ever had a clinical breast exam (CBE)	75.9	80.1	84.7
Ever had a mammogram	52.2	77.5	95.3
Had a mammogram within past 2 yrs	46.2	68.9	89.4
REASONS FOR NEVER HAVING A MAMMOGRAM			
Nobody told them to do so	32.8	20.6	
Too scared	5.0	11.8	
Too young	26.9	11.8	25.0
Other	17.7	41.2	50.0
Refused or no answer given	15.1	14.7	25.0
Don't know what it is	2.5		
CERVICAL CANCER SCREENING HISTORY			
Ever had a pap test	91.6	92.1	96.5

	All Women (n=249) %	All Women Age 40+ (n=151) %	Attendees of Healthy Hopi Women Program Users 40+ (n=85) %
KNOWLEDGE ABOUT BREAST CANCER			
CBE & mammogram are early detection methods	97.2	98.0	98.8
Knows at least 1 symptom	67.9	68.9	72.9
Knows something about how a CBE is performed	83.1	86.8	91.8
Knows something about how a mammogram is performed	70.7	82.1	95.3
Age when mammograms should begin <40	59.4	55.6	62.4
40–50	23.7	27.8	24.7
>50	1.2	2.0	1.2
Don't know	15.7	14.6	11.8
Mammogram should occur yearly	61.0	66.2	69.4
Would like more information	92.7	88.7	91.7
ATTITUDES and BELIEFS ABOUT CANCER SCREENING			
Can take action to reduce own risk of cancer	79.9	80.8	81.2
Early detection of cancer can save lives	97.2	98.0	98.8
CBE can detect breast cancer	71.5	67.6	71.8
Mammogram can detect breast cancer	87.2	88.1	90.6
Embarrassed to be screened for breast cancer	11.2	10.1	5.9
Afraid or worried about screening for breast cancer	15.0	15.65	10.6
Would refuse breast exam if performed by Male	38.9	34.7	31.0
Has refused when performed by male	15.4	15.5	14.7
ATTITUDES TOWARD HOPI WOMEN'S HEALTH PROGRAM (HWHP)			
Comfortable talking with HWHP staff	85.1	86.1	88.2
Ever used HWHP	40.6	56.3	
Would recommend HWHP to others among HWHP users	94.1	94.1	94.1

^a includes cohabitating, common law, and married in traditional way

^b Medical Coverage Excluding Medical Health Services through the Indian Health Service / categories are not mutually exclusive

TABLE 2

Age Adjusted Associations between Characteristics of Hopi Women and Self-reported History of Mammogram Screening Within Past 2 Years, Hopi Women Survey, 2006, Women \geq 40 years of age (Hopi Tribe, USA)

	ALL WOMEN n=151 OR (95% CI)	HWHP USERS n=85 OR (95% CI)
EDUCATION		
< High school	1.00	1.00
High school graduate	1.53 (0.45–5.19)	1.00 (0.03– 31.01)
> High school	1.91 (0.68–5.37)	0.54 (0.05– 5.56)
MARITAL STATUS		
Not Married	0.66 (0.32–1.36)	0.65 (0.15– 2.82)
EMPLOYMENT STATUS		
Employed (full or part time)	0.85 (0.38–1.90)	0.34 (0.05– 2.36)
INCOME		
Income > 25,000	1.28 (0.58–2.84)	1.50 (0.29– 7.82)
PRIMARY LANGUAGE SPOKEN AT HOME		
English only	1.01 (0.47–2.18)	1.39 (0.31– 6.21)
DISTANCE TO CLOSEST MEDICAL FACILITY		
> 10 miles	0.84 (0.41–1.71)	0.28 (0.07– 1.24)
TRANSPORTATION		
Owens a reliable vehicle	2.31 (1.05–5.05)	0.99 (0.18– 5.39)
USES TRADITIONAL HEALER Uses/Ever used	2.49 (1.12–5.36)	3.46 (0.75 –15.87)
SELF AND/OR FAMILY HISTORY OF CANCER		
Any cancer	1.56 (0.77–3.15)	0.63 (0.14– 2.71)
Breast cancer	1.63 (0.54–4.95)	0.83 (0.15– 4.72)
CANCER SCREENING HISTORY		
Ever had a pap test	5.14 (1.39–19.01)	4.52 (1.30– 15.79)
Ever had a clinical breast exam (CBE)	4.65 (1.93–11.18)	3.78 (0.78– 18.38)
CANCER SCREENING KNOWLEDGE		
Of at least one breast cancer symptom	2.17 (1.02–4.63)	2.67 (0.63– 11.30)
Of how a CBE is performed	4.49 (1.63–12.39)	3.47 (1.53– 7.85)
Of how a mammogram is performed	21.96 (6.88–70.05)	8.69 (0.96 –78.56)
That CBE/mammograms are early detection methods	7.04 (0.54–91.90)	1.73 (0.33– 9.10)
CANCER SCREENING BELIEFS		
Early detection can save lives	1.90 (0.26–14.09)	1.14 (0.27– 4.89)
CBE can detect cancer	1.16 (0.54–2.50)	0.32 (0.04– 2.80)
Mammogram can detect cancer	8.00 (2.45–26.17)	2.06 (0.18– 23.20)
BREAST CANCER SCREENING ATTITUDES		
Embarrassed to have exam	0.26 (0.08–0.82)*	0.38 (0.15– 0.98)
Scared to have exam	0.24 (0.09–0.62)*	0.37 (0.06– 2.20)

	ALL WOMEN n=151 OR (95% CI)	HWHP USERS n=85 OR (95% CI)
Would Refuse exam if male provider	0.95 (0.46–1.98)	1.74 (0.33 –9.21)